



A BY US FOR US GUIDE

Young Onset Dementia

An inspirational guide
for people living with dementia

SERIES 1

Introduction

To have a diagnosis of young onset dementia means that you have been diagnosed before reaching the age of 65. The general population often misunderstands young onset dementia because it is considered a condition that affects older adults. However, dementia can affect those in their forties, fifties and sometimes even earlier. People living with young onset dementia face different challenges than those who are older. The most common stigma surrounding young onset dementia is that a person is too young. It is also assumed that young onset dementia progresses quicker. Although this may be the case for some people with young onset Alzheimer's disease (versus Frontotemporal dementia), the changes and the progression vary widely from person to person. When people with young onset dementia do live longer, they may have to deal with people disbelieving that they actually have the correct diagnosis.

Education about the realities of young onset dementia and the changes that come along with it can allow people to decide on the best plan of action for themselves and their families. We hope that by reading the content of this guide, people will learn coping skills and strategies that will work well for them.

**“Life is a choice. I choose not to be bitter,
I choose to be better.”**

(Bea K.)

Emotions

Being diagnosed at a young age can cause many emotions to arise. You may be fearful of what is to come, or be frustrated with learning to deal with the change in your capabilities or adjusting to medications. Maybe you are overwhelmed with all of the new information you are receiving. Your experience of these emotions is normal when living with young onset dementia.

Coping tips and strategies

- ✓ You may find that the emotional aspect of dementia becomes easier to deal with as you learn new coping skills.
- ✓ Try your best to keep a positive outlook on life; it can benefit you and everyone around you!
- ✓ Be aware of your personal stressors:
 - Do your best to avoid overwhelming situations.
 - Alter or adjust to the environment, for example, by removing yourself temporarily.
 - Allow your care partner to provide assistance.

“We are all walking our own path, whether we have the disease or not.”

(Brenda H.)

Family

Family can be one of your best supports when diagnosed at a young age; however, it can also bring along a few challenges. Sometimes family members believe they know best about how to live your life, or sometimes they might be in denial about your diagnosis. Family relationships may have changed, or you may feel like a burden on them because you are limited in the activities that you can do.

Coping tips and strategies

- ✓ Reassure your family that you are still the same person you were prior to your diagnosis.
- ✓ Educate your family (and other care partners) about what you are experiencing and ways in which they can support you.
- ✓ Talk about your diagnosis with your family (and other care partners) and any wishes you have for the future. For example, discuss a change in living situation or financial management.
- ✓ Ask family members to assist you in ways that make sense for you.
- ✓ Continue to make memories with your family.

Brain changes

A diagnosis of dementia can cause confusion in many respects. It is possible that your mind may seem foggy or that you are uncertain about the changes that are occurring. You may also feel hesitant in your thinking; wondering if you are making the right choices. There could also be changes in judgment.

Coping tips and strategies

- ✓ Be patient with yourself.
- ✓ Focus on one task at a time.
- ✓ Be adaptive in your way of thinking. Be ready to make changes based on your “new normal.” Be in the here and now.
- ✓ Ask for simple, step-by-step directions in writing when possible.
- ✓ If verbal directions are provided, ask the person to speak slowly.
- ✓ If you are going somewhere new, ask someone to accompany you the first time. That way, following written directions will be easier the next time. In some cases (if you are experiencing a challenging day), you may need someone to accompany you, rather than relying on verbal or written directions.

Brain changes Continued

Coping tips and strategies

- ✓ Reach out to people you trust, such as a care partner or friends, for their opinion.
- ✓ Keep your brain active. There is more and more proof that brain activities have a positive effect on your mental abilities.
- ✓ Try different ways to keep your brain active:
 - Play online math and/or word games.
 - Sing or play an instrument.
 - Write letters.
 - Read to yourself or someone else.



For more ideas on how to keep your brain active, refer to the By Us For Us guide: **Memory Workout**.

“I push myself and go out and join different groups so not to be a hermit. The brain needs stimulation.”

(Anonymous, person living with dementia)

Physical changes

Many people diagnosed with dementia at a young age are capable of doing many different activities. However, there are still some challenges that you may experience. For example, you may find it challenging to accomplish the same activities in the way you did prior to your diagnosis. You may also experience changes in eating/swallowing, and balance. You could feel as though you are slower in your movements, and that it takes longer to complete an activity. You may also experience other physical issues that are not related to your diagnosis. The important thing is not letting these limitations overcome your desire to remain active.

Coping tips and strategies

- ✓ See your health practitioner if you experience any new physical changes.
- ✓ Take your time; don't worry about what others think of you or your abilities.
- ✓ Continue to do the activities you love. Learn new ways to accomplish them.
- ✓ Pay close attention to your surroundings. For example, shadows and changes in the texture or design of the floor could be tripping hazards.

Physical changes Continued

Coping tips and strategies

✓ Find ways to stay physically active:

- Call a friend to join you on a walk.
- Participate in simple exercises, such as chair exercises, tai chi, dance, etc.
- Take your pet to the park.



For more tips on how to stay safe inside and outside your home, refer to the By Us For Us guide: **Living Safely** and **Safety When Out and About**.

Notes

“People fall into the mindset that after a diagnosis that it’s all downhill from here. My advice is to keep living life!”

(Brenda H.)

Social exclusion

Social interactions might change after receiving a diagnosis of dementia, particularly when diagnosed at a young age. You might be required to retire early from your career due to difficulties in performing your job. This could be isolating for some individuals whose job is a large part of their daily social interactions. Relationships with friends may also shift due to their reaction to your diagnosis or having to make accommodations for you.

Coping tips and strategies

- ✓ Be open and honest. Let people know you are still capable of doing many things; you might just need to do them in a different way or with assistance.
- ✓ Look to join group activities that you enjoy and that make you feel part of the community.
- ✓ It is okay to listen and not feel required to join into conversation.
- ✓ Try your best to keep connected with others.

“This is the way it was planned for me.”

(Annette H.)

Independence

Being diagnosed at a young age with dementia can feel as though you are losing your independence. You might see yourself as relying highly on others to assist you in tasks that you were previously able to accomplish independently. Make a plan to prepare yourself for any changes you may experience as your abilities shift, and update it regularly.

Coping tips and strategies

- ✓ Be proactive. Educate yourself on what supports are available, as you may need more as your needs change. For example, changes in living situations, cooking, etc.
- ✓ Let others know of your whereabouts.
- ✓ Consider carrying a cellphone with you.
- ✓ Look for support groups where you can get insight from others living with dementia.

“Hope for the best, prepare for the worst.”

(John H.)

Transportation

Transportation means freedom for many people. Not being able to “get-up-and-go” may make a person feel as though they have lost some of their independence. When diagnosed at a younger age, it is important to think about alternative transportation. Having measures in place when you are first diagnosed can reduce stress.

Coping tips and strategies

- ✓ Learn about public transit in your area:
 - Look for maps or download the transit App for the area you are travelling in.
 - Do test runs of transit routes with a friend to places you travel to often (i.e. grocery store, pharmacy, etc.).
 - Know the transit stop you want to get on and off at.
 - Try to be alert and look out for your stop!
 - Ask the driver to assist you by letting you know when you arrive at your stop.
- ✓ Look into whether your municipality has services to aid in transportation for people living with dementia.
- ✓ Find activities you enjoy that are within walking distance or accessible by public transit.

Transportation Continued

Coping tips and strategies

✓ If you drive:

- Look into getting a GPS (Global Positioning System) that can provide step-by-step directions.
- Be aware of distractions and avoid conversations that can take away your concentration.

✓ Pace yourself when travelling:

- Plan your trip ahead of time and take regular breaks.
- Do your best to avoid rush hour traffic.
- Conserve energy by not filling your day with too many tasks.
- Listen to signs from your body on when you need to stop.
- If possible, ask someone to join you when travelling.

“For a person who has driven the miles I have, sitting in the passenger seat is just glorious.”

(Anonymous, person living with dementia)

Finance

When diagnosed with young onset dementia it is important to consider how your financial situation may change. Many people living with dementia do not wish to feel as though they are depending on their families or friends for financial support. So, it is important to find solutions that work for you and allow you to keep a comfortable lifestyle as you age.

Coping tips and strategies

- ✓ Look into local government resources that exist in your area that could provide you with some assistance.
- ✓ Ask friends or peers that may know of resources available locally.
- ✓ Look on the Internet for accessible support in your area.
- ✓ When shopping:
 - Use debit or credit.
 - Carry small bills and coins.
 - Ask the store clerk to double check that the amount you paid is correct.

Finance Continued

Coping tips and strategies

- ✓ When paying bills:
 - Set up a reminder system.
 - Arrange automatic bill payments.
 - If using online banking or writing cheques, have someone check that your transactions are correct.
 - Put a maximum limit on your credit card.
 - Put a maximum daily or weekly limit on your debit card.
- ✓ Find a financial advisor you trust, and who will speak with you about your personal situation separately from family members.
- ✓ Designate a power of attorney (POA) to act on your behalf when you are no longer able to look after your own finances.
- ✓ Consider making a living will, if this corresponds with your wishes.

“You can’t progress in anything without hope.”

(Brenda H.)

Identity and self-worth

Living with dementia does not dictate your worth. Though your experiences may bring along with it a loss of confidence and identity, you are still in control of your life. You know yourself best and can learn skills that will benefit you. You have ownership over your body and the care that you receive.

Coping tips and strategies

- ✓ Ask questions when you visit doctors or specialists. They should be happy to give you answers.
- ✓ Have advanced care directives in place to ensure your desires are known.

Notes

“I chose today to live happily with what I can do.”

(Bea K.)

Care, support, and services

It is important to take care of your mental health when diagnosed with young onset dementia. Putting in effort to care for yourself is vital for your well-being.

Coping tips and strategies

- ✓ Use technology to your advantage. This can be helpful in keeping your mind occupied.
- ✓ Continue educating yourself (e.g., reading, having discussions with others, joining in community or group activities).
- ✓ Take advantage of your physical health; go for walks, participate in sports, or other hobbies that you enjoy.
- ✓ Reach out to friends and family members and talk about your diagnosis; talk about how everyone involved feels.
- ✓ Take a step back and be mindful of verbal communication (e.g. spoken words) and non-verbal communication (e.g. body language). Think about how it may affect each person in the conversation.
- ✓ Help decrease the stigma attached to young onset dementia by sharing your experience. When you share your knowledge, you encourage others to learn more about young onset dementia.

Conclusion

Throughout this guide, people who have experienced young onset dementia provided tips and strategies in hopes of helping others. The three main points they believe help in working through a diagnosis of young onset dementia are: **learning acceptance, gaining self-awareness, and pacing yourself.**

Young onset dementia requires more research to provide a better understanding of the diagnosis. We hope you will consider sharing your knowledge and experience with others to educate them about the diversity amongst people living with dementia. You can tell others about the best ways of approaching and dealing with feelings, as well as the changes that you experience when diagnosed at a young age. Share the ways in which you cope as well as the tips and strategies you learned in this guide.

“Your attitude can make all the difference in the quality of your life.”

(Brenda H.)

“Tell your story to one person to create a ripple effect. You are being an advocate in doing this.”

(Brenda H.)

Brenda's story: The inspiration behind the By Us For Us Guides

When Brenda Hounam was diagnosed with Alzheimer's disease at the age of 53, she realized that very little information was available for people living with dementia. The dominant view was that people living with dementia could no longer learn and be involved in their own care. Brenda knew differently. In 2003, she was inspired to address this gap - to develop a series of resources specifically designed by and for people living with dementia. In 2004, she approached two of her peers with her idea and was surprised by the enthusiasm and support they offered. Through Brenda's contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas, and the Murray Alzheimer Research and Education Program (MAREP), Brenda connected with various people living with dementia from all around Ontario to work on what came to be called, the "By Us For Us" (BUFU) guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for themselves and others living with dementia. Since the publication of the first guide, "Memory Workout", the following guides focused on issues raised by people living with dementia. The project has grown to include three series researched and developed in partnership with people living with dementia and care partners. The philosophy of the By Us For Us guides remains committed, placing importance first on the experiences, suggestions, and tips from those directly affected BY dementia, FOR those directly affected. Brenda has been a true inspiration and role model to her peers. Without her determination and perseverance, this project would not exist or have the international recognition that it does.

Celebrating 15 years!

The year 2019 marks the 15th anniversary of the inception of the By Us For Us guides! On this occasion, we would like to acknowledge the original development team members that came together in 2004 to produce “Memory Workout” – the very first By Us For Us guide that was eventually published in 2006. It is because of this team that the By Us For Us project continues today.



Photo: The original members of the development team.
(Standing from left)—Gail Robinet, Scott Millar, Elaine Smith,
Norm Wilson, Sharon Smith

(Seated from left)—Rupert Inch, Brenda Hounam

(Missing from photo)—Don Hayes

Resources

To learn more about dementia visit:

Alzheimer Society of Canada

Toll-free telephone: 1-800-616-8816

Email: info@alzheimer.ca

Website: www.alzheimer.ca

World Health Organization

Website: www.who.int

Endorsements

Too often, people diagnosed with young onset dementia fall through the cracks. This guide, specifically written BY people with young onset dementia FOR people with young onset dementia, fills a gap in the necessary information and support that people with young onset dementia need. True to the spirit of “nothing about us without us”, the BUFU guides are critical in helping people living with dementia to live well with their diagnoses by giving us an inside glimpse into the kinds of strategies that people living with dementia find useful for themselves. As a researcher and academic, I recommend these resources to many people living with dementia, family care partners, and even health and social service providers. Congratulations, MAREP team, on another wonderful BUFU guide!

Dr. Elaine C. Wiersma, PhD

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Associate Professor, Department of Health Sciences
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As a physician and educator in dementia care, I wish to congratulate the “By Us For Us” team for the development of this excellent resource guide for individuals living with young onset dementia. It is especially significant that this guide was entirely researched and written by persons living with dementia. It is written in a way that is understandable and concise, and offers a wealth of practical advice and strategies. Particularly important are the tips and strategies for coping with social and emotional aspects of dementia and how to live well. This guide is highly recommended reading for persons and family members dealing with young onset dementia.

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About the By Us For Us Guides

The By Us For Us Guides (BUFU guides) are designed to provide people living with dementia/care partners the necessary tools to enhance their well-being and manage daily challenges. What makes these guides unique is that they are created BY people living with dementia/care partners, FOR people living with dementia/care partners. The guides include three unique series:

People Living with Dementia: Series 1

This series is written by people living with dementia and covers their experiences. It includes topics such as tips and strategies for managing daily challenges, memory exercises, and enhancing communication and wellness.

Partnership: Series 2

This series is written by both people living with dementia and care partners and covers the partnership experience. It includes topics such as safety, food and mealtimes, social connections, and coping with loss and grief.

Care Partner: Series 3

This series is written by care partners and covers their experiences of supporting a person living with dementia. This series includes topics such as before diagnosis, young care partners, roles, and health and wellbeing.

To view other guides or order print copies, please visit the Schlegel-UW Research Institute for Aging website:
www.the-ria.ca

We welcome your input...

If you are living with dementia or are a care partner and would like to comment on this guide, suggest topics for future guides, or participate in future guides, please contact Murray Alzheimer Research and Education Program (MAREP).

Connect with us!

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